



Learning from the patient

**Gemma Winsor &
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Ferring Pharmaceuticals have reviewed these slides for
technical content

Disclosures

Learning from the Patient

Gemma Winsor and Uma Lanka

In relation to this presentation, the authors and presenters above have no conflicts of interest that need to be disclosed.

Why co-production?

Co-production is a way of working that involves people in an equal partnership, engaging groups of people at the earliest stages of service design, development and evaluation.



Patient Panels



Patient Engagement Toolkit

**CROHN'S &
COLITIS UK**

FIGHTING
INFLAMMATORY
BOWEL DISEASE
TOGETHER

Give now

Join us

About Inflammatory
Bowel Disease

Support for you

Get involved

Research

Improving health
services

Healthcare
Professionals

Toolkit for Healthcare
Professionals



QUESTION: Do you engage patients in improving your service?

1. Yes

2. No

QUESTION: Do you engage patients in improving your service?

1. Yes



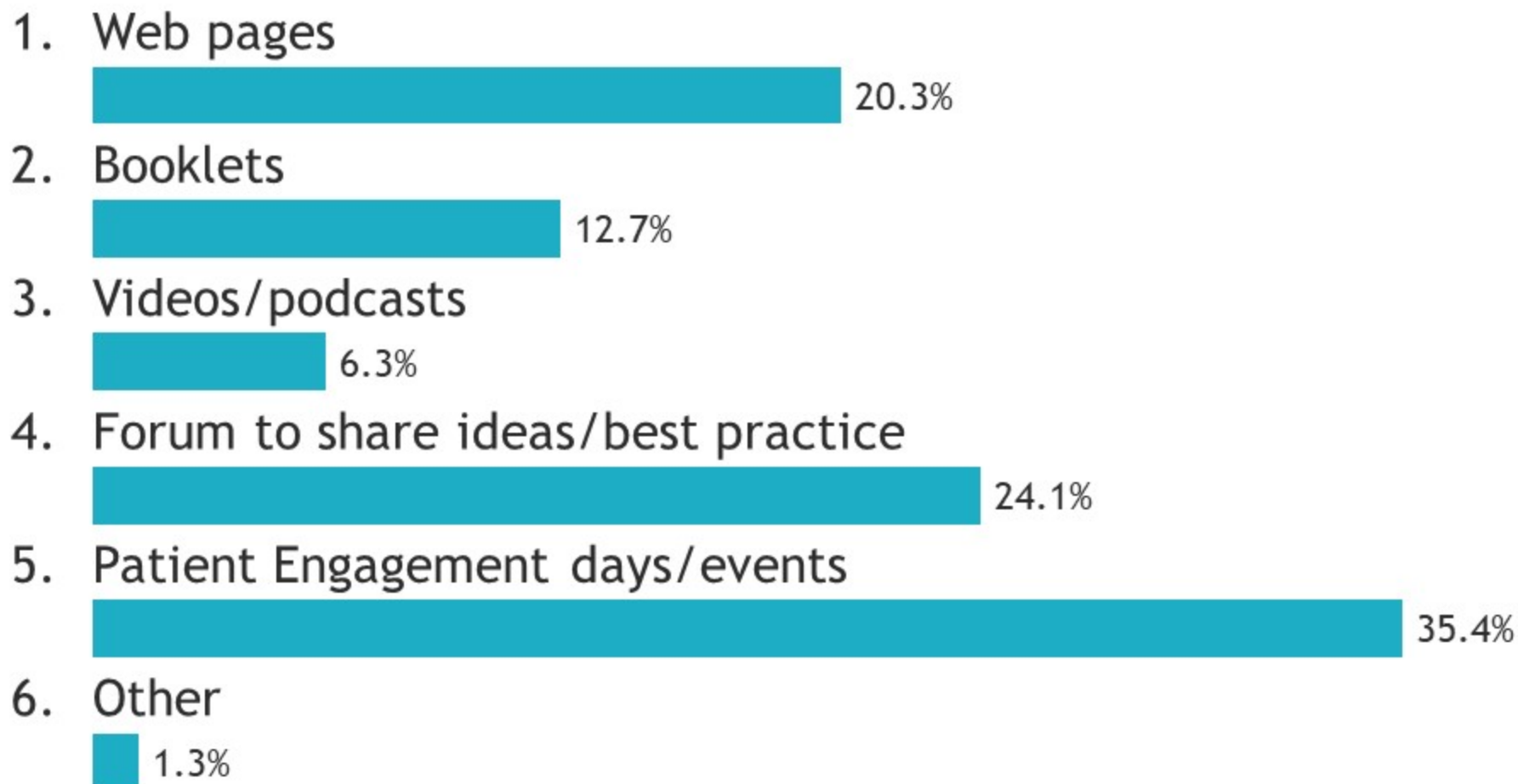
2. No



QUESTION: What resource would be most useful to you?

1. Web pages
2. Booklets
3. Videos/podcasts
4. Forum to share ideas/best practice
5. Patient Engagement days/events
6. Other

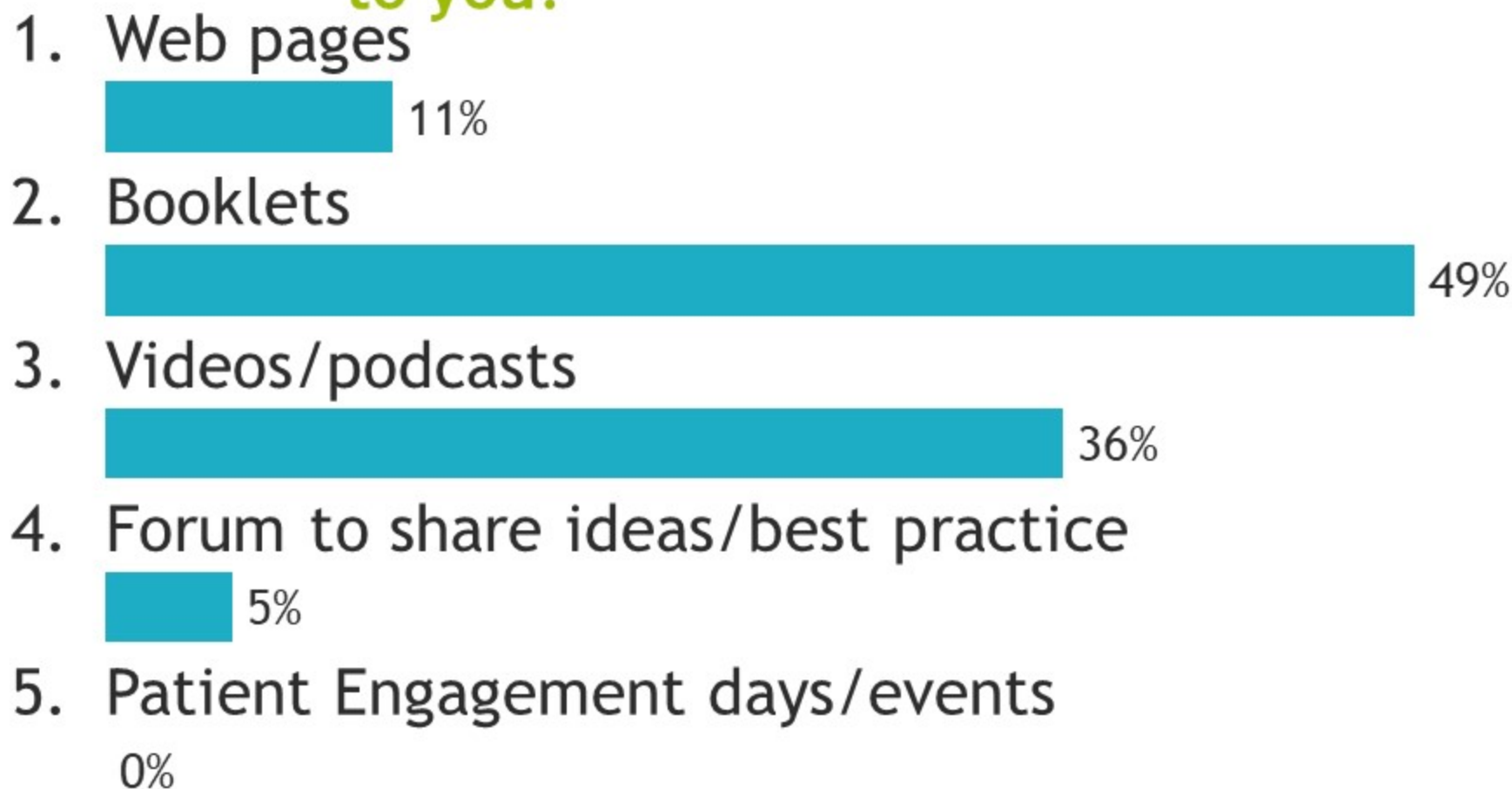
QUESTION: What resource would be most useful to you?



QUESTION: What resource would be least useful to you?

1. Web pages
2. Booklets
3. Videos/podcasts
4. Forum to share ideas/best practice
5. Patient Engagement days/events

QUESTION: What resource would be least useful to you?



IBD Patient Survey update

Extended closing date
22nd November 2019



SECTION 1: ABOUT YOU

Firstly, please tell us about ...

- Which of these options describes you or the person on whose behalf you are completing the survey? **Please choose one option**
- In which hospital have you received the majority of your Crohn's or Colitis care?

☐ **I have Crohn's Disease**
Crohn's Disease causes inflammation of the gut (digestive system). Crohn's can affect any part of the gut, though the most common area affected is the end of the ileum (the last part of the small intestine), or the colon.

☐ **I have Ulcerative Colitis**
Ulcerative Colitis causes inflammation and ulceration of the inner lining of the rectum and colon (the large bowel).

☐ **I have Microscopic Colitis**
Microscopic Colitis affects the large bowel (colon and rectum). There are two main forms: Lymphocytic Colitis and Collagenous Colitis.

☐ **I have Inflammatory Bowel Disease (IBD) Unclassified / Indeterminate Colitis**
Also known as indeterminate colitis, or as colitis of uncertain type or etiology (CUTIE). You may be described as having IBDU if it is unclear whether you have Crohn's Disease or Ulcerative Colitis.

☐ **I have symptoms but a hospital specialist has yet to confirm that I have Crohn's or Colitis**

☐ **I do not have Crohn's or Colitis**

Please do not complete the survey if a hospital specialist has yet to confirm that you have Crohn's or Colitis, or you do not have Crohn's or Colitis.

Thank you for your interest in the IBD Patient Survey, however we are only collecting data from individuals with a confirmed diagnosis of Crohn's or Colitis, as the questions in this survey relate directly to the new IBD Standards. For further information on Crohn's or Colitis, our work and how to get involved, please visit the IBD UK website www.ibd.uk.org

Please note: For simplicity, we will refer to all diagnoses as Crohn's and Colitis for the rest of the survey.

Your answers will help us to understand how the services provided by this hospital to people with Crohn's and Colitis are performing. If you have NOT recently received hospital care or are not under the care of an IBD service, please write the hospital you live nearest to.

- When was your last contact with this service? **Please choose one option**

☐ Within the last 12 months
☐ 1-2 years ago
☐ More than 2 years ago
☐ Never had contact
☐ Don't know/Can't remember

- How old are you? **Please choose one option**

☐ 0-17 years old
If you are under 18, you will need to ask a parent, carer or guardian to give consent and complete the survey together.
☐ 18-24 years old
☐ 25-34 years old
☐ 35-44 years old
☐ 45-54 years old
☐ 55-64 years old
☐ 65-74 years old
☐ Over 75 years old
☐ Prefer not to say

**CROHN'S &
COLITIS UK**



Crohn's and Colitis Education Programme

Feedback from patients

‘Excellent talk, really informative. Answered many questions I'd got, and many more that I didn't know. Thanks.’

‘It was really interesting for me (American) to see how you do things differently in the UK.’

‘Talked very simplistically. Very informative. Felt comfortable to ask questions.’

“Very, very helpful. Crucial information included here which wasn't obtained anywhere else that I've looked for 23 years.’

‘I thought the session was really useful. Although I didn't ask any questions, I feel like my mind was settled. Thank you.’

Support from Crohn's & Colitis UK

Our helpline offers advice about symptoms, medication, accessing welfare benefits and more:

Call: **0300 22 5700**

Email: **helpline@crohnsandcolitis.org.uk**

Livechat: **crohnsandcolitis.org.uk/livechat**

Monday – Friday, 9am – 5pm

Thank you.

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